

HUMAN DIGNITY IN THE 'VEGETATIVE' STATE

By Richard M. Doerflinger

On Christmas Eve, 1999, the family of Patricia White Bull in Albuquerque, New Mexico received an unexpected gift. After 16 years in a supposedly irreversible "vegetative state," Mrs. White Bull began to speak.

"Don't do that," she blurted out when nurses were trying to fix her nursing home bed. Then she started speaking her children's names, catching up on family developments, and eating foods she had not been able to swallow for many years. Her mother says her sudden recovery is a Christmas miracle from God (*The Washington Times*, January 5, 2000, p. A3).

Mrs. White Bull's story is not unique. In recent years, a number of patients have unexpectedly recovered from the "vegetative" state - a dimly understood condition in which patients have sleep/wake cycles, but do not seem aware of themselves or their environment. And according to medical experts speaking at a March 2004 international congress on the "vegetative state" in Rome, medical science is only beginning to realize how little is understood about this condition.

The term "persistent vegetative state" was coined in 1972. Physicians said then that patients with this diagnosis had no consciousness or sensation, and could not recover once they had remained in this state for a certain number of months. The latest findings contradict all this. It turns out that patients diagnosed as being in a "vegetative" state may have significant brain waves, and substantial parts of the upper brain may be alive and functioning. This functioning may even change depending on whether a friend or relative is speaking nearby. The testimony of many families that their loved ones in this state seem to know when they are present can no longer be dismissed as simply wishful thinking. And medical experts are

no longer so confident that they can name a number of months or years in this state that makes some degree of recovery impossible.

On March 20, 2004, near the end of the Rome conference on the "vegetative" state, Pope John Paul II delivered an important speech in an audience with the attendees. This speech clarified and reaffirmed our moral obligation to provide normal care to these patients, including the food and fluids they need to survive. Here the Holy Father made several points:

1. No living human being ever descends to the status of a "vegetable" or an animal. "Even our brothers and sisters who find themselves in the clinical condition of a 'vegetative state' retain their human dignity in all its fullness," he said. "The loving gaze of God the Father continues to fall upon them, acknowledging them as his sons and daughters, especially in need of help." Against a "quality of life" ethic that makes discriminatory judgments about the worthiness of different people's lives, the Church insists that "the value of a man's life cannot be made subordinate to any judgment of its quality expressed by other men."

2. Because this life has inherent dignity, regardless of its visible "quality," it calls out to us for the normal care owed to all helpless patients. In principle, food and fluids (even if medically assisted, as in tube feeding) are part of that normal care. Such feeding, he said, is "a *natural means* of preserving life, not a *medical act*." This means, among other things, that the key question here is simply whether food and fluids effectively provide nourishment and preserve life, not whether they can reverse the patient's illness. Even incurable patients have a right to basic care.



3. This judgment does not change when the "vegetative" state is diagnosed as "persistent" or unlikely to change: "The evaluation of probabilities, founded on waning hopes for recovery when the vegetative state is prolonged beyond a year, cannot ethically justify the cessation or interruption of *minimal care* for the patient, including nutrition and hydration."

4. Deliberate withdrawal of food and fluids to produce a premature death can be a form of euthanasia, that is, unjust killing. "Death by starvation or dehydration is, in fact, the only possible outcome as a result of their withdrawal. In this sense it ends up becoming, if done knowingly and willingly, true and proper euthanasia by omission."

5. The Church's traditional teaching, that one is not obliged to impose useless or excessively burdensome treatments on patients, remains valid. The obligation to provide assisted feeding lasts only as long as such feeding meets its goals of providing nourishment and alleviating suffering. But to those who might too easily withdraw such feeding as overly burdensome, the Holy Father warns that "it is not possible to rule out *a priori* that the withdrawal of nutrition and hydration, as reported by authoritative studies, is the source of considerable suffering for the sick person." If a seemingly unresponsive patient might be able to feel the burdens of tube feeding, he or she may also be able to feel the suffering of being dehydrated to death.

6. We must not forget the needs of families caring for a loved one in a "vegetative" state. The rest of us must not abandon these families, but reach out to give them every possible assistance so they will not face their burdens alone. Respite care, financial support, the sympathetic cooperation of medical professionals and volunteers, and psychological and spiritual comfort were among the kinds of help the Holy Father urges society to provide.

The Pope's speech responds to a serious moral and legal problem that has divided families, ethical advisors, and courts in the United States and elsewhere. For many years, "right-to-die" groups have promoted the withdrawal of assisted feeding from patients in a "vegetative" state. Sometimes they have admitted that they see such patients as better off dead (or at least see their families as better off if the patients are dead). Ethicist Daniel Callahan warned in the *Hastings Center Report* in October 1983 that many of his colleagues favored such policies not because of special burdens involved in such feeding, but because "a denial of nutrition may in the long run become the only effective way to make certain that a large number of biologically tenacious patients actually die." In some of the "tube feeding" court cases that have divided families and sparked headlines, even some family members have declared that the patient is essentially already dead - an "empty shell" with no human dignity.

Church officials have warned against this trend in the past. In 1992, for example, the U.S. bishops' Committee for Pro-Life Activities issued a resource paper titled "Nutrition and Hydration: Moral and Pastoral Reflections," recommending a strong presumption in favor of assisted feeding for patients diagnosed as being in the "persistent vegetative state." The paper strongly opposed any removal of these means designed to hasten the patient's death from dehydration or starvation. It also found that assisted feeding is generally not "extraordinary means" - rather it is usually an effective way to sustain life that does not impose grave burdens on patients. Similarly, a 1995 "Charter for Health Care Workers" issued by the Pontifical Council for Pastoral Assistance to Health Care Workers stated: "The administration of food and liquids, even artificially, is part of the normal treatment always due to the patient when this is not burdensome for him: their undue suspension could be real and properly so-called euthanasia."



M A D E I N H I S I M A G E

RESPECT LIFE PROGRAM

By reaffirming these principles, the Holy Father is reminding us that here, as on issues such as abortion, embryo research and capital punishment, the Church's voice must be raised to insist that every human being is a beloved child of God, that no one is worthless or beyond our loving concern.

This does not mean that patients must accept tube feeding in cases where they would see it as an unwarranted intrusion that only increases their suffering. When discussing the burdens and benefits of medical procedures, the Church has always recognized that these judgments have a subjective element, and that patients' own assessments are to be given great weight. In the final analysis, as Pope Pius XII said in a 1952 address to the medical community, "the doctor has no other rights or power over the patient than those which the latter gives him."

At the same time, the obligation to respect human life in every condition is addressed to all of us, including patients. Catholics should beware of "advance directives" that reject assisted feeding across the board; rather, we should seek out more carefully worded documents that recognize the presumption in favor of such care when it does not impose undue burdens on the patient. Many state Catholic conferences have produced statements on this issue, or even sample forms allowing Catholics to specify their wishes in ways that reflect Catholic values and conform to any requirements of state law. Forms allowing the patient to name a trusted proxy decision maker, to make decisions when the patient can no longer do so, may be more helpful than a written declaration that tries to anticipate all future medical situations.

Hospitals and physicians, for their part, should not be obliged to comply with a request from patient or family that they believe is immoral. The *Ethical and Religious Directives for Catholic*

Health Care Services state that a Catholic hospital "will not honor an advance directive that is contrary to Catholic teaching," and adds: "If the advance directive conflicts with Catholic teaching, an explanation should be provided as to why the directive cannot be honored" (Directive 24).

When would such a directive conflict with Catholic teaching? When it ignores the general obligation to support and care for human life, and treats a condition like the "vegetative" state, in and of itself, as a basis for withdrawing even the most basic measures for preserving the patient's life and comfort. In an extreme case, it may be obvious that the document is rejecting assisted feeding simply to ensure that the patient in such a condition dies as soon as possible.

Patients and families, like others involved in medical decisions, need to understand that while specific medical procedures may at times become useless or burdensome, this can never be said of human persons themselves. Caring for loved ones who may never be able to respond or thank us for our faithfulness could be the ultimate test of our commitment to a culture of life.

Richard M. Doerflinger is Deputy Director of the Secretariat for Pro-Life Activities, U.S. Conference of Catholic Bishops.

PROGRAM MODELS

Celebrating Life: Holding Sacred the Human Spirit is a faith-based program directed toward Pastoral Care Ministers and other professionals who minister to persons facing the end of life as well as their loved ones. The presentation is designed in a "train the trainers" format in hopes that the program will be replicated in parishes throughout the diocese. The objectives of the program are to educate those who encounter end of life questions with answers that follow Catholic teaching, specifically regarding nutrition and hydration, legal issues, and family concerns. For more information on this program please contact the Bonnie Seaver, Director of Diocese of St. Augustine's Respect Life Office at (904-262-3200 x.126) or Bill Tierney, Director of Catholic Charities (904-262-3200 x. 123).

Being With® is a charitable project which offers true compassion, wantedness, and love to those faced with physical suffering in hospitals, nursing facilities, hospices, and homes. A *Being With*® volunteer spends their time quietly, by the side of the suffering person, listening, smiling, singing, reading, laughing, watching television, listening to a ballgame, or even just being present while a person falls asleep. When appropriate, we sometimes hold a patient's hand, or caress someone's arm or forehead. Sometimes we cry. Always we love. In the future, *Being With*® will train health care professionals and volunteers who wish to create a real environment of peace, purpose, and dignity among those who suffer from chronic, serious, or terminal illnesses or injuries.

For more information about the *Being With*® project, visit their website at www.beingwith.net or P.O. Box 1900, Snohomish, WA 98291, phone: 360-668-0333.

In 2002, the Arlington Diocese published an advanced medical directive which complies with the laws of the Commonwealth of Virginia and the moral teachings of the Catholic Church. Contained in

a striking folder, the diocese provides a blank Advanced Directive and a Supplement to the Directive which answers questions concerning the completion of the document, the terminology used in the document, and the disposition of the document. The Office for Family Life of the Diocese distributes these to individuals and parishes throughout the diocese. Directives are available postpaid for \$3.00 each by check to: Family Life Office, 200 North Glebe Road, Suite 523, Arlington, VA 22203. For more information, contact (703) 841-2550.

In Support of Life is a Power Point presentation developed to aid parishioners and medical professionals in the Church's teaching on end-of-life issues, exposing the threats to patients in this critical time and discussing living wills. Contact the Diocese of Venice at 941/441-1101 or by email berdeaux@dioceseofvenice.org.

Family Support: Parish communities can pull their resources together to support families giving round-the-clock care to loved ones through volunteering their talents and providing outlets for a family who may feel isolated from society. Parishes can offer not only spiritual counseling and pastoral aid, but also nights out for the primary care-givers, a friendship and most importantly compassion.

Use All Souls Day, November 2nd, as a focal liturgical time of year to educate your parish about the importance of end-of-life issues. Have pamphlets available for parishioners to take as they leave Mass. Some suggestions are: *Hope for the Journey: Meaningful Support for the Terminally Ill* and *The Gift of Life...in the Face of Death*. Both are available from the USCCB by calling 866-582-0943. The Nebraska Catholic Conference developed a pamphlet on *Medical Treatment Decision Making* which you can order from them (402/477-7517), or download the text at http://www.nebcathcon.org/press_releases.htm#Med.

PROGRAM RESOURCES

Teaching Documents

Address to the Participants in the International Congress on "Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas."

Pope John Paul II, March 20, 2004. Available at: http://www.vatican.va/holy_father/john_paul_ii/speeches/2004/march/documents/hf_jp-ii_spe_20040320_congress-fiamc_en.html

The Dignity of Dying People. Pontifical Academy for Life, 1999. Reprinted in *Origins*, Vol. 28, No. 41 (\$2.95 to download).

The Gospel of Life. Pope John Paul II, 1995. Washington, D.C.: USCCB. Also in Spanish (\$7.95).

Declaration on Euthanasia. Sacred Congregation for the Doctrine of the Faith, 1980. Available from Secretariat for Pro-Life Activities (50 cents).

Guidelines for Legislation on Life-Sustaining Treatment. NCCB Committee for Pro-Life Activities, 1984. Secretariat for Pro-Life Activities (60 cents).

In the Service of Life. Pontifical Council for the Family, 1992. Washington, D.C.: USCCB (\$1.25).

Nutrition and Hydration: Moral and Pastoral Reflections. NCCB Committee for Pro-Life Activities, 1992. Secretariat for Pro-Life Activities (\$1.95). Can also be found at <http://www.usccb.org/prolife/issues/euthanasia/nutindex.htm>.

On the Christian Meaning of Human Suffering. Pope John Paul II, 1984. Washington, D.C.: USCCB (\$3.95).

Statement on Euthanasia. NCCB Administrative Committee, 1991. Secretariat for Pro-Life Activities (\$7/100; \$65/1,000).

Print

A Catholic Guide to End-of-Life Decisions. Brighton, Mass.: The National Catholic Bioethics Center, 1998 (\$2; quantity discounts).

The Case against Assisted Suicide: For the Right to End-of-Life Care. Kathleen Foley, M.D. and Herbert Hendin, M.D. (eds). Baltimore: The Johns Hopkins University Press, 2002 (\$49.95)

Euthanasia and Physician Assisted Suicide: Killing or Caring? Rev. Michael Manning, M.D. Mahwah, N.J.: Paulist Press, 1998 (\$8.95).

Handbook for Mortals: Guidance for People Facing Serious Illness. Joanne Lynn, M.D. and Joan Harrold, M.D. New York: Oxford University Press, 1999 (\$25).

Last Rites: Assisted Suicide and Euthanasia Debated. Michael M. Uhlmann (ed). Grand Rapids, Mich.: Wm. B. Eerdmans, 1998 (\$35).

Lessons from the School of Suffering: A Young Priest with Cancer Teaches us how to Live. Rev. Jim Willig and Tammy Bundy. Cincinnati, Ohio: St. Anthony Messenger Press, 2001 (\$6.95).

Life's Worth: The Case against Assisted Suicide. Arthur J. Dyck. Grand Rapids, Mich.: Wm. B. Eerdmans Publishing Co., 2002 (\$20.00).

Moral Issues in Catholic Health Care. Kevin T. McMahon, S.T.D. (ed.), Wynnewood, Penn.: Saint Charles Borromeo Seminary, 2004.

Power over Pain: How to get the pain control you need. Eric M. Chevlen, M.D. and Wesley J. Smith. Steubenville, Ohio: International Task Force in Euthanasia, 2002 (\$12.95).

Right to Die versus Sacredness of Life. Kalman J. Kaplan (ed.). Amityville, N.Y.: Baywood Publishing Co., 2000 (\$31.95).

Stations of the Cross for the Sick. Catalina Ryan McDonough. Bloomington, Ind.: Our Sunday Visitor, Inc. (\$4.95) May be ordered from www.osv.com.

When Death Is Sought: Assisted Suicide and Euthanasia in the Medical Context. Report of the New York State Task Force on Life and the Law (updated, 1999). Albany, NY: Health Education Services (\$10).

Newsletters, Pamphlets, Reprints

A Catholic Guide to Medical Ethics: Catholic Principles in Clinical Practice. Eugene F. Diamond, M.D., Palos Park, Illinois: The Linacre Institute, 2001. Visit www.cathmed.org.

Explaining Catholic Teaching: Euthanasia. Philip Robinson, London: The Incorporated Catholic Truth Society & The Linacre Centre, 2003. Visit www.linacre.org.

The Gift of Life ...in the Face of Death. Secretariat for Pro-Life Activities, 1998, pamphlet (\$9/100; \$80/ 1,000).

Hope for the Journey: Meaningful Support for the Terminally Ill. Kathy Kalina, RN, CRNH. Secretariat for Pro-Life Activities, reprint, 2001 (#0101-KAL; 40 cents; 10-49 copies, 30 cents ea.; 50+ copies, 25 cents ea.).

Killing the Pain, Not the Patient: Palliative Care vs. Assisted Suicide. Richard M. Doerflinger & Carlos Gomez, M.D. Secretariat for Pro-Life Activities, reprint, 1998 (#9801-DOE; 40 cents; 10-49 copies, 30 cents ea., 50+ copies, 25 cents ea.).

In Support of Life: Comfort and Hope for the Dying. Brochure. Massachusetts Catholic Conference (50 cents; quantity discounts).

Oregon's Assisted Suicide Experience: Safeguards Don't Work. Oregon Right to Life. Salem, Ore.: Omega Publications (25 cents; quantity discounts).

Audiovisual

Euthanasia: False Light. Steubenville, OH: Intl. Anti-Euthanasia Task Force, 1995. Excellent discussion featuring physician, hospice nurse, and three patients who survived "terminal illness" (\$24.95).

Final Blessing. Washington, D.C.: USCCB, 1997. Thought-provoking documentary on the spiritual dimensions of the lives of terminally ill persons (\$29.95).

Life at Risk: A Closer Look at Assisted Suicide. Twelve audiotapes of 1997 symposium of international experts at Catholic University of America, co-sponsored by the NCCB, The Catholic University of America and the Center for Jewish and Christian Values. Available from Donehey & Associates (\$50 per set in an album; individual tapes available at \$5 ea.).

Physician Assisted Suicide: Not Worth Living? Colorado Springs: Focus on the Family/ Gospel Light (\$20.00).

Internet

Papers presented at the International Congress on Life-Sustaining Treatments and Vegetative State are available at www.vegetativestate.org.

www.acponline.org/journals/news/sept98/suicide.htm (American College of Physicians)

www.ama-assn.org/ama/pub/category/8288.html (American Medical Assoc. Code of Ethics)

www.cathmed.org (Catholic Medical Assn.)

www.healthinaging.org/public_education/pain (American Geriatrics Society Foundation for Health in Aging)

www.iaetf.org (Intl. Anti-Euthanasia Task Force)

www.kofc.org/faith/cis/028/sacredlife.cfm (Knights of Columbus Catholic Information Service)

www.ncbcenter.org (Nat'l Catholic Bioethics Center)

www.ncpd.org (Nat'l Catholic Office for Persons with Disabilities)

www.nrlc.org (Nat'l Right to Life Committee)

www.nursesforlife.org (Nat'l Assn. of Pro-Life Nurses)

www.seniorhealthcare.org (Senior Health Care Organization)

www.stemcellresearch.org (Coalition of Americans for Research Ethics)

www.usccb.org/prolife (USCCB Secretariat for Pro-Life Activities)